

Thalidomide Embryopathy Swedish Study 1987 - 2009

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Associated documentation

File_tree_SND_1256.txt (114.73 KB)

List_of_examinations_and_examination_history_SND_1256.txt (851 bytes)

TE_Questionnaire_Studie2_SND_1256.pdf (473.84 KB)

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Description

Since the end of the 1980s a number of studies have been performed at the University of Gothenburg of individuals born in Sweden with birth defects caused by Neurosedyn (Thalidomide Embryopathy - TE). Two pediatric ophthalmologists Kerstin Strömmland at the University of Gothenburg, Sweden and Marilyn Miller at the University of Illinois in Chicago USA, performed the initial studies while other researchers have been involved in later studies. We collected data from medical records from their childhood and performed scrutinized examinations of the affected individuals with documentation through photos and videos. These studies of a considerable number of individuals with TE have been recognized as probably being the only of its kind in the world and international researchers have suggested that the data ought to be archived for future studies in teratology.

The first step in this procedure was the Thalidomide Archives Project (TAP) made by Teratology Society (later renamed Society for Birth Defects Research and Prevention). By permission of 16 patients suffering from TE, study data from medical records, examination protocols, photos and videos as well as a Webinar have been archived and made available for members of Teratology Society. It is not permitted or possible to copy any documentation.

The present archived material includes digitized data from two studies of the Swedish population of TE (Neurosedyn).

Study 1 was performed 1987-1989 and consisted of 86 Swedish individuals born with TE and it had a focus on ophthalmology.

Study 2 was performed 2007-2009 by a multidisciplinary team of experts in ophthalmology, speech pathology, orthopedics, dentistry and neuropsychiatry. Thirty-one individuals with TE were examined of whom 25 who had participated in Study 1 are included in this documentation. The data originate from the ophthalmological examinations.

Physical data in the study are archived at the University of Gothenburg, archive number 180:1, Institute of Neuroscience and Physiology, series F4A.

Contents and structure

1. Code list (21-05-21_Code list.xlsx)

Pseudonymized information on case number, sex, information about available documents and about participation in Thalidomide Archives Project (TAP) (in English).

2. Study 1 - Overview of archived material (2021-05-21_TE_Overview.xlsx)

Data on 86 individuals with TE : case number, year of birth, sex, malformation of ears, hearing, facial palsy, Duane syndrome, gaze paresis, tearing when eating and emotionally, primary position of eyes, visual acuity, other eye findings, malformation of thumbs, upper and lower extremities and vertebrae, malformation of heart, lungs, kidneys, anal atresia, other malformations, intellectual disability, autism, combination of defects and number of tablets taken by mother (in English).

3. Study 1 - Anamnestic data (2021-05_21_Study 1_TE History.xlsx)

Data on the mother's pregnancy, intake of Neurosedyn tablets, heredity, early development, schooling, occupation/social, and data on tearing function (in English).

4. Study 1 - Results of eye examination (2021-05-21_Study 1_TE Physical examination.xlsx)

Mostly unpublished data (in English).

5. Study 1 - Results of eye examination (Scanned examination protocols, 123 files, 85 individuals)

Complete data (in English).

6. Study 2 - Results of eye examination (Scanned eye examination protocols, 23 files, 23 individuals) (in English).

7. Study 2 - Questionnaire answered by participants (Scanned documents, 20 files, 20 individuals) (in Swedish).

8. Copies of medical records (scanned documents, 82 files, 82 individuals)

Medical reports and certificates from guardians that formed the basis of the decisions for the Board of the Thalidomide Association (Neurosedynskadenämnden) (Swedish text).

9. Study 1 and 2 - Cropped photos (PDF files, 84 files, 84 individuals)

Photos of face, eyes, eye movements, ocular fundus, ears and malformed extremities. The photos are cropped to shelter the identity of the individuals.

10a. Study 1 and 2 - Digitized original photos (jpg-files, individuals 1-86, varying number of files per individual)

Photos of face, eyes, eye movements, ocular fundus, ears and malformed extremities. Photos from Study 1 were scanned from diapositive slides.

10b. Studie 1 - Video recordings (.wmv files and one .mpg file, 21 individuals)

Interviews and documentation of common situations.

Data contains personal data

Yes

Sensitive personal data

Yes

Type of personal data

Survey data, photographs, videos, medical assessments, medical records.

Code key exists

Yes

Language

[English](#)

[Swedish](#)

Unit of analysis

[Individual/Patient](#)

Population

Individuals with thalidomide embryopathy (n=86) born in Sweden

Study design

Observational study

Sampling procedure

[Total universe/Complete enumeration](#)

Time period(s) investigated

1987-01-01 - 2009-12-31

Number of individuals/objects

86

Data format / data structure

[Numeric](#)

[Text](#)

[Still image](#)

[Video](#)

Data collection 1

- Mode of collection: Observation
- Time period(s) for data collection: 1987 - 1989
- Source of the data: Registers/Records/Accounts: Medical/Clinical, Research data: Published, Research data: Unpublished, Population group, Geographic area, Registers/Records/Accounts, Research data

Data collection 2

- Mode of collection: Observation
- Time period(s) for data collection: 2007 – 2009
- Source of the data: Registers/Records/Accounts: Medical/Clinical, Registers/Records/Accounts: Academic/Aptitude, Events/Interactions, Research data: Published, Population group, Geographic area, Registers/Records/Accounts, Research data

Geographic spread

Geographic location: [Sweden](#)

Lowest geographic unit

Country

Highest geographic unit

Country

Responsible department/unit

Institute of Neuroscience and Physiology

Ethics Review

Gothenburg - Ref. Ö 556_03

Research area

[Medical and health sciences](#) (Standard för svensk indelning av forskningsämnen 2011)

Keywords

[Ophthalmology](#), [Thalidomide](#), [Prenatal injuries](#), [Neurosedyn](#)

Publications

Strömmland K, Nordin V, Miller M, Akerström B, Gillberg C. Autism in thalidomide embryopathy: a population study. *Dev Med Child Neurol*. 1994 Apr;36(4):351-6.

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If you have published anything based on these data, [please notify us](#) with a reference to your publication(s). If you are responsible for the catalogue entry, you can update the metadata/data description in DORIS.

Polygon (Lon/Lat)

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Accessibility level

Access to data through SND

Access to data is restricted

Use of data

[Things to consider when using data shared through SND](#)

Versions

Version 1. 2021-10-26

Download metadata

[DataCite](#)

[DDI 2.5](#)

[DDI 3.3](#)

[DCAT-AP-SE 2.0](#)

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